An evaluation of an evidence-based online screening tool to help identify learning disability

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Abstract

Aim: Many people with a learning disability are unable to benefit from health improvement measures because their learning disability is unrecognised. Screening tools, such as the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q), can offer a way to help. We evaluate the accuracy of a new, online version of the CAIDS-Q.

Methods: Anonymous data from those who had used the online CAIDS-Q in the first weeks of the launch (15th January - 3rd February 2020) were collated and analysed.

Results: Of the 159 people who used the online CAIDS-Q, 126 (79.2) were family/carers of the person that the CAIDS-Q was being completed about and 31 (19.5%) were professionals. Of the 52 people who were reported as having been previously identified as having a learning disability, 47 (90.4%) were correctly identified as such by the CAIDS-Q score.

Conclusion: The accuracy of the online version of the CAIDS-Q was similar to that found with hard copy versions, suggesting it may offer an accurate tool to help identify people with a learning disability.

Keywords: learning disability, screening, CAIDS-Q, online

Background

Despite the introduction of primary care learning disability registers and reasonable adjustments, such as annual health checks, people with a learning disability, continue to experience significant health inequalities. Figures for 2017/18 suggest that fewer than half of those with a learning disability received a flu vaccination and just over half received an annual health check (NHS Digital,

2016). In order for people with a learning disability to benefit from such initiatives, they need to be identified as having a learning disability in the first place, but figures suggest that the majority go unrecognised (Emerson and Glover 2012).

There have been attempts to identify people with a learning disability in primary care by using diagnostic codes from general practice records (e.g. Allgar et al 2008, Russell et al 2017). Such methods have the advantage of using existing information and not requiring clinical staff input, but these approaches are thought to miss a significant number of people with a learning disability (Allgar et al 2008).

Last year, NHS England and NHS Improvement (2019) published guidance for primary care staff with the aim of improving identification of people with a learning disability. This guidance provided a revised and extended list of diagnostic codes to be used in combination with a 21-item 'Learning Disability Register Inclusion Tool.' Users are instructed that "Several 'yes' answers could indicate the presence of a Learning Disability," although 'several' is not defined, and the accuracy and psychometric properties of the tool have not been established. Without this information and an evidence-based cut-off score that indicates whether the person is likely to have a learning disability or not, the Inclusion Tool is likely to be of limited benefit. Identifying that someone is likely or unlikely to have a learning disability can have a significant impact in terms of access to support and resources. Any tools that are designed to help identify learning disability, should, therefore, meet the same standards, in terms of strong psychometric properties and good sensitivity and specificity as standardised assessments (Glascoe 2007).

Validated screening tools for learning disability do exist. The Child and Adolescent Intellectual Disability (CAIDS-Q) was developed for children and young adults. This is short, quick and easy to use, has an evidence-based cut-off score, good sensitivity, specificity, and psychometric properties when used in a range of settings (e.g. McKenzie et al 2012, 2013, 2019). They also have

positive benefits for services and those being screened (McKenzie et al 2019a) and do not require the person using it to have a training or background in learning disability.

An online version of the CAIDS-Q was recently included on a new free webapp designed to provide families and professionals with access to a wide range of resources about learning disability (Learning Disability Matters for Families: https://learningdisabilitymatters.co.uk/tools/). A webapp is a website that is designed so that it can be viewed easily on a smartphone, but via any internet browser, rather than needing to be downloaded or installed on a specific device. The webapp was publicised using various means, including a launch day, via organisational websites and tweets, such as Inclusion North (https://tinyurl.com/y8wbjsty), North East and Cumbria Learning Disability Network (https://twitter.com/necldnetwork?lang=en) and primary care services (e.g. https://tinyurl.com/ybthrhxr). It can also be found via internet searches for information about learning disability.

This development provided the opportunity for a pilot evaluation of the accuracy of the CAIDS-Q with a population that was not all clinically referred. A question was included that asked whether the child/young person had previously been identified by a health or education professional as having particular conditions, with learning disability as one of the options. This information provided an indication of whether the CAIDS-Q, as used in an online context, provided feedback based on the cut-off score, which was consistent with the self-report of whether the person had been identified as having a learning disability or not. The aim of the pilot project was, therefore, to explore whether the CAIDS-Q identification of whether someone was likely to have a learning disability or not was consistent with the self-report of those using it online in a non-clinical population. If so, this may indicate that the online CAIDS-Q may be useful in helping identify those who should be on the learning disability register and entitled to reasonable adjustments in health care.

Method

Design

The pilot project used an observational, correlation design. Ethical approval for the project was obtained from the first author's university ethics committee. All data were completely anonymous and collected routinely as part of the online system.

Participants

Participants were those people who completed the online CAIDS-Q. They were not identifiable in any way. Data from the first few weeks of the launch of the online CAIDS-Q were used for the study (between 15th January and 3rd February 2020). The full sample comprised 159 people. A subsample (n = 52), who were reported as having been previously identified by a health or education professional as having a learning disability, were included in the second aspect of the analysis. This aimed to explore the agreement between this self-reported learning disability and the CAIDS-Q outcome.

Measures

The measure used was the CAIDS-Q, which comprises seven short questions about the literacy, support needs, relationships and basic skills of the child or young person, which are answered 'yes' or 'no.' The results are used to calculate a score, which is then compared to the cut-off score for the child's age, to indicate whether it is likely that he/she has a learning disability or not. The CAIDS-Q has been found to have strong psychometric properties in a range of different settings (McKenzie et al 2012, 2013, 2019). The online version has some additional questions, including those outlined below, the scoring is carried out automatically and the user is provided with immediate feedback about whether the person is likely to have a learning disability or not. The feedback also provides some guidance on the types of local services that users can contact to ask for advice if they have concerns about the child. The webapp also has a section on 'Getting help' which provides a range of

resources and links to organisations that offer support and advice. The online version can be accessed at: https://learningdisabilitymatters.co.uk/learning-disability-form/

Information was gathered about whether the person completing the CAIDS-Q was a family member/carer, professional or 'other'; the age and gender of the child about whom it was being completed; whether he/she spoke English as a second language, whether a health or educational professional had previously said the child had a condition (options were learning difficulty, autism, learning disability, physical disability, none or other) and the 'yes' or 'no' responses to the CAIDS-Q questions. On completion of the CAIDS-Q the user received immediate feedback about whether the score indicated that the child/young person was likely to have learning disability or not.

Procedure

The routinely collected, anonymous data was downloaded into an excel spreadsheet and subsequently SPSS for analysis. Duplicate data (as indicated by the person entering the same code and all other information) and test data by the website developers were removed, as was data that suggested that the user was trying out the CAIDS-Q, but not using it in relation to an actual child. This was indicated by the user entering a date of birth that had the same day and month as the date the CAIDS-Q was completed.

Analysis

The data for the full sample were analysed using descriptive statistics, to provide an overview of those using the online CAIDS-Q. The data from the subsample of those who reported that a professional had previously classified the child/young person as having a learning disability were used to explore the agreement between this reported classification and the CAIDS-Q classification. Percentage agreement was used, to allow comparison with previous results, and Kappa was used to take account of agreement that may have been due to chance. The criteria used by Landis and Koch (1977) were used to interpret the Kappa result.

Results

A total of 190 people completed the CAIDS-Q between 15th January and 3rd February 2020. When duplicate and 'test' data were removed, 159 participants remained. Of these, 126 (79.2) were family members or carers of the person that the CAIDS-Q was being completed about, 31 (19.5%) were professionals, and two (1.3%) were 'other' (friends). In terms of those about whom the CAIDS-Q was completed, ages ranged from 6-18 (M = 10.4, SD = 3.7), 94 (59.1%) were male, 65 (40.9%) were female and 13 (8.2%) were reported as having English as a second language. Table 1 provides information about the number and type of conditions that those that the CAIDS-Q was completed in relation to were reported as having.

Table 1: Number and type of conditions that those that the CAIDS-Q was completed in relation to were reported as having.

Number of conditions	**None**	**One**	**Two**	**Three**	**Four**
	4	76	2	19	2
Type of condition	**Autism**	**Learning Disability**	**Learning Difficulty**	**Physical Disability**	**Other (e.g. epilepsy)**
	69	52	46	25	15

Of the total group, 50 (31.4%) were indicated by the CAIDS-Q score as likely to have learning disability, 102 (64.2%) were identified as not likely to have a learning disability, but the score indicated they were likely to have some difficulties with their intellectual or adaptive functioning, 7 (4.4%) were identified as unlikely to have a learning disability.

The sub-group comprised 52 children/young people about whom it was reported that a professional had previously classified them as having a learning disability. Thirty-three (63.5%) were male and 19 (36.5%) were female. The most commonly reported co-occurring condition was ASD, which was reported for 19 (36.5%) of the children. Ages ranged from 6 to 18 (M = 10.6, SD = 3.4). Six (11.5%) spoke English as a second language.

Of the 52 children/young people who were reported by the person completing the form as already being known to have a learning disability, 47 (90.4%) across all age groups were correctly identified as such by the CAIDS-Q score. All but one of the children who were incorrectly identified as not having a learning disability received feedback that they were identified as not likely to have a learning disability, but their score indicated they were likely to have some difficulties with their intellectual or adaptive functioning.

The results of the analysis using Kappa, indicated significant and 'almost perfect' agreement (Landis & Koch, 1977); Kappa = .885, $p<.001$.

Discussion

A number of authors have highlighted the need for better systems for identifying people with a learning disability, particularly those with moderate and mild learning disabilities (e.g. Glover and Emerson 2012). This pilot study aimed to explore the characteristics of those using the online CAIDS-Q and of the children/young people about whom it was being completed. A further aim was to obtain an initial indication of the extent to which the CAIDS-Q classification agreed with a previous identified learning disability. Both aims were in the context of helping to inform whether the CAIDS-Q would be a useful, accurate, and evidence based way for helping health staff to identity those people who were likely to have a learning disability and who would, therefore, benefit from being on primary care learning disability registers.

The results indicate that the majority of those using the online CAIDS-Q were family members or carers. Of the total sample, 52 (31.4%) were indicated as having a learning disability. This is much higher than the 2.2% total population figure, but is perhaps unsurprising, given that the CAIDS-Q was accessed from a webapp that was designed for families who had children with, or who had concerns that their children might have, a learning disability.

In respect of the sub sample, the CAIDS-Q identified 90.4% of those who had previously been indicated as having a learning disability as having one. This figure is consistent with the sensitivity figures found in research in health settings (McKenzie et al 2013, 2019). Of the five children who were not identified as likely to have learning disability, all but one, were given the feedback that the score indicated that the child was likely to have some difficulties. Two of the young people were aged 17 and 18 and it may be that the adult version of the screening tool, the LDSQ, may be more suitable for this older group. It is unclear why the CAIDS-Q was used in relation to some children who had already had their learning disability identified. This may have been to test the accuracy of the CAIDS-Q using the details of someone whose learning disability was already known, in order to have confidence in the results when used in relation to someone whose learning disability status was unknown.

Implications for practice

Identifying that a person is likely to have a learning disability has a number of potential benefits for the individual and health services. They can be offered specialist and/or additional support as required, entered on the learning disability register when old enough and receive reasonable adjustments, such as flu vaccinations and annual health checks. Research indicates that health checks can identify previously undiscovered conditions that are potentially amenable to treatment (NHS Digital 2016). In addition, they have not been found to be associated with increased costs for service use (Romeo et al 2009). The early identification of new or underlying health issues and preventing problems becoming chronic and more severe are also likely to reduce the need for potentially more expensive input in the future (Robertson et al 2011).

There are, however, ethical issues to consider. Learning disability can be a stigmatising condition (Paterson et al 2011), and a classification of likely learning disability may, therefore, not always be welcome, particularly if the person was not aware that this was a possibility (Allgar et al 2008). One of the potential advantages of the online CAIDS-Q is that many of those who completed

it were family members, suggesting they already had concerns that the child/young person had a learning disability and may be better prepared for confirmation of the possibility.

While early identification of children with a learning disability is particularly important to facilitate access to early interventions that can benefit their functioning, health, and quality of life (Guralnick 2017, McKenzie et al 2019a) research suggests that the majority of adults with a learning disability are unknown to services. Even when people are identified as children as having a learning disability, this status frequently goes unrecorded and is lost when the person reaches adulthood, the process described as the 'transition cliff' (Emerson and Glover 2012). The adult version of the screening questionnaire, the LDSQ similarly used in an online format, may offer an accurate and evidence-based means of helping to identify this overlooked group of adults.

Limitations

There were a number of limitations with the study. As noted above, those who accessed the webapp and used the online CAIDS-Q are more likely to have concerns about their child, and are, therefore, unlikely to be representative of the general population. However, as the CAIDS-Q is aimed at those who have concerns that the person might have a learning disability, it is important to evaluate its accuracy in this group. A second limitation is that the previous identification of learning disability was based entirely on the self-report of those using the online CAIDS-Q and we do not know to what extent this is correct. Future research which verifies the classification of learning disability is needed to address this. Similarly, it was not possible to assess the specificity of the online CAIDS-Q from the available data, i.e. those who were correctly classified as not being likely to have a learning disability. Again, future research that conducts full assessments on a subgroup of those falling into this category would help address this limitation. Finally, as with all screening tools, the CAIDS-Q is not a diagnostic tool and full assessment by an appropriately qualified professional is always needed to confirm whether the person meets the criteria for learning disability or not.

Conclusion

A significant barrier to people with a learning disability receiving good health care is that their learning disability is not recognised. In this paper, we explored the use of an online version of a screening tool for learning disability that can be used by professionals and parents and found that it correctly identified 90.4% of those who had previously been indicated as having a learning disability. The online tool may be useful for nurses in a range of services to help identify people who might benefit from inclusion in learning disability registers and reasonable adjustments in health care

Implications for Practice
• The online CAIDS-Q is a freely available resource which can potentially help nurses, other professionals and families identify that a person is likely to have a learning disability • This has a number of benefits for the person being identified, including timely access to further health and educational assessment and support as required. • Online access to the CAIDS-Q means it can reduce the need for face to face contact, which may be helpful in in the current context of Covid-19

Conflict of interests

The first author was a co-developer of the CAIDS-Q and receives a small payment for its use.

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